



## DEPARTMENT OF HEALTH AND HUMAN SERVICES

### Health Resources and Services Administration

#### **Agency Information Collection Activities: Proposed Collection: Comment Request**

#### **Action: Notice**

**Summary:** In compliance with the requirement for opportunity for public comment on proposed data collection projects (section 3506(c)(2)(A) of Title 44, United States Code, as amended by the Paperwork Reduction Act of 1995, Public Law 104-13), the Health Resources and Services Administration (HRSA) publishes periodic summaries of proposed projects being developed for submission to the Office of Management and Budget (OMB) under the Paperwork Reduction Act of 1995. To request more information on the proposed project or to obtain a copy of the data collection plans and draft instruments, email [paperwork@hrsa.gov](mailto:paperwork@hrsa.gov) or call the HRSA Reports Clearance Officer at (301) 443-1984.

HRSA especially requests comments on: (1) the necessity and utility of the proposed information collection for the proper performance of the agency's functions, (2) the accuracy of the estimated burden, (3) ways to enhance the quality, utility, and clarity of the information to be collected, and (4) the use of automated collection techniques or other forms of information technology to minimize the information collection burden.

**Information Collection Request Title: Organ Donation/Transplant Life Stories (OMB No. 0915-xxxx) – [New]**

**Abstract:**

HRSA's Division of Transplantation (DoT) is the primary entity in the Department of Health and Human Services (HHS) responsible for the Organ Transplant Program established under the National Organ Transplant Act (Public Law 98-507, codified at sections 371- 377D of the Public Health Service (PHS) Act). Section 377A of the PHS Act authorizes the Secretary of HHS to establish a public education program to increase awareness about organ donation and the need to provide for an adequate rate of such donations. In brief, DoT's responsibilities are two-fold: 1) to provide oversight and guidance to the national organ transplant system in the U.S. including monitoring the Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients, and 2) to implement a program of public and professional education and outreach aimed at increasing the number of organ donors in this country. Many preventable deaths occur each year because of a staggering imbalance between the supply and demand for donor organs. As of November 2012, the national transplant waiting list exceeded 116,000. In 2011, the total number of deceased and living organ donors was only 14,145. These donors enabled 28,538 patients to receive a transplant while 6,693 died waiting. Without successful interventions to increase donation, the disparity between need and supply is likely to be substantially exacerbated, resulting in even more unnecessary deaths.

Organdonor.gov is DoT's primary mechanism for providing the public with information about organ donation. Among the most visited pages on organdonor.gov are the donor and recipient life stories, which in a recent evaluation study were shown to raise interest on the topic, and,

more importantly, persuade people to register as organ donors. To expand this component of [organdonor.gov](http://organdonor.gov), DoT proposes to develop an application to give organ recipients and donor families the opportunity to voluntarily submit their stories to DoT via a standardized online form. The online form will be posted on [organdonor.gov](http://organdonor.gov) and will collect demographic and contact information, the individual's donation/transplant story up to 500 words, a high-resolution photo, and a signed authorization. The standardized, electronic form will increase HRSA staff's ability to process those stories more efficiently. In addition to enabling story submission, the online application process will make the donor and recipient life stories posted on the site searchable by the public to enhance public viewing and understanding of the organ donation process. Submission of a story and completion of the form is voluntary. Overall, this application has the potential to strengthen DoT's outreach efforts and increase organ donation registration in the United States.

**Burden Statement:** Burden in this context means the time expended by persons to generate, maintain, retain, disclose, or provide the information requested. This includes the time needed to review instructions, to develop, acquire, install and utilize technology and systems for the purpose of collecting, validating and verifying information, processing and maintaining information, and disclosing and providing information, to train personnel and to be able to respond to a collection of information, to search data sources, to complete and review the collection of information, and to transmit or otherwise disclose the information. The total annual burden hours estimated for this Information Collection Request are summarized in the table below.

The annual estimate of burden is as follows:

Form Name	Number of Respondents	Number of Responses per Respondent	Total Responses	Average Burden per Response (in hours)	Total Burden Hours
Donation/ Transplantation Life Story Submission Form	100	1	100	0.25	25
Total:	100	1	100	0.25	25

**Addresses:** Submit your comments to [paperwork@hrsa.gov](mailto:paperwork@hrsa.gov) or mail the HRSA Reports

Clearance Officer, Room 10-29, Parklawn Building, 5600 Fishers Lane, Rockville, MD 20857.

**Deadline:** Comments on this Information Collection Request must be received within 60 days of this notice.

Dated: January 9, 2013

Bahar Niakan

Director, Division of Policy and Information Coordination

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